



# E - NEWS

A program of the  
National Hospice and Palliative Care Organization



## ChiPPS Pediatric Palliative Care Newsletter – Issue #7; May, 2007

Edited by Charles A. Corr, Ph.D., CT, and Christy Torkildson, RN, PHN, MSN

### Perinatal Loss

The subject of this issue of the newsletter (as it was for the previous issue) is perinatal loss. Here is a brief Table of Contents highlighting the articles included in this issue and offering a brief description of each piece.

#### **Perinatal Palliative Care: Lighting the Way for Families through a Difficult but Sacred Journey of Beginnings and Endings**

p. 2

Liz Sumner, RN

*This article looks at the history of perinatal palliative care with the view of palliative care as a “lifespan” issue not an age issue. The article offers practical suggestions for implementing strategies to support for families facing perinatal/neonatal loss.*

#### **Current and Emerging Issues in Perinatal Loss and Birth Planning for Parents facing Difficult Circumstances**

p. 7

Ann Fitzsimons, BS, MBA, and Beth Seyda, BS

*This is the second part of a series highlighting key insights from the 15<sup>th</sup> National Perinatal Bereavement Conference held in Chicago in 10/06 by PLIDA, the Pregnancy Loss and Infant Death Alliance. Two presentations are summarized in this brief article. The first deals with some old and new types of unspoken losses suffered by mothers perinatally, at birth, or postnatally. The second focuses on perinatal hospice and the need for birth planning, what they are, and how to help families with a birth plan when a terminal prenatal diagnosis is evident.*

#### **The NICU: A Different World**

p. 13

Missy Stamper

*Missy shares her moving story of the birth of her son Nathan, a 30-week premature infant, life in the NICU, and lessons learned from her very special son. A true story with lessons for us all.*

#### **Obstacles to Optimal Palliative Care in the Labor and Delivery Unit**

p. 16

Gay Gale, RNC, MS, and Alison Brooks, RN, MS, CNS

*This article describes the development of a model Perinatal Palliative Care program at Alta Bates Summit Medical Center in Berkeley, CA, including challenges and a call for action.*

#### **Providing Emotionally Supportive Care to Parents as They Face Decisions after Prenatal Diagnosis of a Baby’s Life-Limiting Condition**

p. 22

Deborah L. Davis, PhD

*Deborah L. Davis, Ph.D., author of Empty Cradle, Broken Heart and Loving and Letting Go, writes eloquently about providing a safe “holding” environment for parents and maintaining therapeutic boundaries.*

#### **Frequently Asked Questions: Perinatal Loss**

p. 26

Donna Armstrong, MSW

#### **Educational Resources**

p. 28

Karen Paradise Baranowski, RN

\* \* \*

ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics).



---

## Perinatal Palliative Care: Lighting the Way for Families through a Difficult but Sacred Journey of Beginnings and Endings

### Liz Sumner, RN

Palliative Care Program Coordinator, The Elizabeth Hospice

[LHSumner@elizabethhospice.org](mailto:LHSumner@elizabethhospice.org)

*“The woman conceives. As a mother she is another person than the woman without child. She carries the fruit of the night...in her body. Something grows. Something grows into her life that never again departs from it. She is a mother. She is and remains a mother even though her child dies, though all her children die. For at one time she carried the child under her heart. And it does not go out of her out ever again. Not even when it is dead.”*

*Author unknown.*

*Source: Hygeia Foundation*

“In the beginning...” there was hope.

There is joy and expectation of the arrival of a baby, maybe weeks or months to come. Then the world forever changes for the parents (and many around them) when they discover there is something wrong, something seriously wrong with their unborn baby. For many the pregnancy will end by medical intervention and yet for others the journey continues on in a very isolated path.

Many parents find themselves quite literally on this path alone from this point on when they choose (for a variety of reasons) to continue the pregnancy. “Why would you want to go through that agony and grief? Why would any one decide to see that through? Just get it over with and spare yourself the grief.” Parents in perinatal hospice programs across the country share common experiences of being chastised and even criticized or harshly judged for their decision to continue the pregnancy even with a poor prognosis or expected outcome. These parents have come to this decision from a variety of paths. Some have quickly bonded, attached many feelings and reactions to their unborn baby, felt movement, heard the heartbeat, and had immense hopes for this life.

In reality there is no escaping grief whether it comes immediately by terminating the pregnancy or later on from miscarriage or stillbirth or fetal demise or if the baby dies soon after birth. “How much is too much to bear” is very personally defined, a decision that is bound in religious, spiritual, social, emotional, and cultural influences.

But in hospice care we are committed to accompanying the patient and family on *their* journey even when there seems to be an absence of hope. For these families with a prenatal diagnosis that may be life threatening for their baby, the *uncertainty* of outcome should be inclusionary criteria for perinatal palliative care support not an exclusionary one. It is in fact this uncertainty that lends itself to the wonderful safety net of care and support that a palliative care approach can bring to the family's experience. They can benefit from the "guide" role of the team—navigating the decisions unique to their situation, with all the people involved, the settings for care, and the many relationships that are impacted by this pregnancy and family. The team can guide them with the dual nature of their goals—



## Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care  
Organization



preparing for both birth and possibility of death; the blended emotions of hope and fear, grief and joy. Planning for both the best and worst possibilities.

The model of palliative care often promotes “best practice” when integrated from time of diagnosis of a life-threatening condition throughout the illness, and then if the person/child dies, into bereavement. Since palliative care is a “lifespan *issue*” not secluded to the elderly, it is needed at the very beginning of life as well, when life and death share each other’s company. This approach can accommodate the needs, concerns, and unique experience of parents who know from that fateful day in a genetics counseling or MD office that their hopes may drastically change or be adapted to a new reality. The uncertainty or confirmation of the actual severity of the condition is usually not known until baby arrives. There is a legitimate place for the supportive role of palliative care for these families—to address the spiritual suffering, the fear and grief, and yet the opportunity to be in control of what they can to normalize their limited time with their baby. Advanced care planning discussions are very beneficial to create a “Birthing plan” detailing goals for labor, delivery, and the immediate newborn period, to anticipate and discuss the desired intensity of care. Some options will be discussed during pregnancy with the primary care provider to determine what is possible, reasonable, and perhaps contraindicated or not going to benefit their baby’s unique situation. Help for children in the family is critical, for they, too, will have and lose a sibling. Good perinatal palliative care can help them understand what is wrong with baby and what they can do to be helpful, while also identifying their requirements at home and school to meet their daily needs, provide support, and maintain their routines

Almost a million birth/pregnancy-related tragedies occur each year through miscarriages, fetal demise, stillbirths, and newborn death. The number is exponentially greater when you consider the additional lives impacted directly or indirectly from these brief but shared lives: husbands and wives, siblings, grandparents; co-workers, friends of all family members, close friends, neighbors, faith community friends and acquaintances; medical providers. There are many mourners and uncomfortable participants in this all too common and all too dismissed group of losses.

Perinatal losses may be anticipated such as with a prenatal diagnosis of a serious condition or anomaly or a sudden and acute crisis event. These brief “lifetimes” impact each individual and family uniquely. There are gender differences in how couples respond and express their reactions to these losses, there are cultural and religious influences on the experience, and there are family norms or patterns that contribute to how one copes with, expresses, and integrates the death.

There has been significant progress in NICUs and Birthing centers for the bereavement care offered, protocols have been developed for what to do when a baby dies, fetal demise, miscarriage, and stillbirth. There are steps to follow and tasks to be completed; there are memory boxes or footprints saved. There are education and expectations. Formal and informal leaders in this very sensitive area have emerged in clinical settings—those who are known as “the ones who will work with those parents” when a baby has died or may die. Regardless of the practice or written policy, the most important and memorable ingredient in this time is HOW the parents felt as a result of the words, behaviors, and personal attention given by the medical providers. The negative impressions are devastatingly hurtful and initiate a painful recovery process that may last for decades. Many parents speak of the thoughtless expressions of words or lack of attention to privacy, sensitivity, setting, and pace of care that they have difficulty shedding after leaving the medical setting. By contrast, parents will recount with fine detail the tenderness in the gentle touch, the soft voice, and the respectful consideration for time, space, and tenderness when their baby lived and/or died.



# Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care  
Organization



Some models for perinatal palliative care begin at time of diagnosis from referrals by genetic counselors or from MD offices, and follow family with intermittent visits during pregnancy, follow at time of delivery with team presence, doula support, attending MD appointments, etc. Others initiate care at time of arrival for delivery; still others see it as bereavement support following the death.

Indeed we should be mindful of the “Rights of Parents when a baby dies” as the National SHARE office has created. They remind us and in fact direct us to adhere to the following recommendations:

- Create opportunities for parents to see, hold, and touch their baby—before or after death
- Have pictures taken that are lasting images
- Give as many mementoes and keepsakes as possible
- Name and fulfill the bonding experience they are able to have
- Observe important practices and rituals they need to fulfill
- Provide care by empathetic, respectful staff
- Create time/space for them to be alone if they wish
- Plan a farewell ritual or service to their preferences, desires, or beliefs
- Make possible access to bereavement support services and follow-up from subsequent resources, groups, etc., as they desire

As pediatric hospice and palliative care programs increase their outreach into the community of providers, it is important to integrate the very specialized professionals and local resources that care for, and support the pregnant woman and her family; high risk pregnancies, the birthing centers, the genetic counselors, perinatologists, and ethics committees; pregnancy counselors; community-based grief resources, and doulas. We can both benefit from their expertise and insights as well as share ours with them to enhance their own model of care. Together we form a more collaborative and seamless continuum of care for those who need it most, those who are truly vulnerable and fragile, large in number yet markedly invisible in our midst. By extending our resources to this population and group of families we can broaden the impact and services of palliative care. The umbrella of palliative care services can surely be extended to enfold these families and those who care for them into the security, clinical excellence, and healing approach we strive to accomplish with each person we serve.

Families will benefit from the team approach to decision making, preparation of family members, focus on what normalcy they can, planning for memory-making tasks they wish for; advanced care planning with parents and physician for the baby after delivery; informed discernment and discussion of intensity of care desired.

Perinatal palliative care can shed light on the dignity and treasure in this briefly lived life and shelter the family from the path that lengthens and accentuates the hurt from their loss.

Preserving tangible keepsakes: keep in mind all of the senses that are possible to imprint memories and to further the family's ability to find their way back to them when they need or wish to over the years to come.

1. Photographs
  - Of baby, of family/parents and baby
  - Of baby's hands and parents and/or siblings
  - Of baby and parents' hands



## Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care  
Organization



- Different angles to capture all views of baby
  - Wrapping baby to expose best features
2. List of guests/visitors to hospital
  3. Keepsake certificate from hospital
  4. Blanket that baby was wrapped in
  5. Hospital bracelets—parent's and baby's
  6. Bassinet ID card
  7. Lock of baby's hair
  8. Footprints, handprints, finger prints; ear-prints; lip prints (with non paint)
  9. Audio recording of baby's sounds if born alive
  10. Art paper outline of baby's body—body tracing
  11. Front page of newspaper for birth-day
  12. Family portrait of hand prints with baby's
  13. Gather baby's clothes and place in zip lock baggies to preserve scent.

The death of a child is never easy to witness or experience, even for the professionals caring for the child/family. It is frequently an emotionally intense and often humbling encounter that makes a lasting impact on all. What can make a powerful difference is *how* we are present in attending to the needs of the immediate situation, their basic needs at the time we encounter this type of death experience. Bringing our knowledge, compassion, humanness, and some practical ideas will go a long way to providing a safe and comforting setting for those impacted by the baby's death.

Understand that the words they hear and how they are treated often stays with them for years, even decades to come. For some the story carries with them even to the end of their own lives on hospice or palliative care as elderly adults. It all matters! Even if you feel really sad, even scared at the rawness of these encounters, remember what you feel is NOTHING like what they are experiencing. An emotional posture of humility and grace is the most fitting reverence for their sorrow and their journey that only they can travel. Do not fill the empty space with the "wrong words" just because it aches in the quiet; your presence and your gentle touch or listening is often more healing than any words you might speak.

*Although we know that after such a loss the acute state of mourning will subside, we also know we shall remain inconsolable and will never find a substitute. No matter what may fill the gap, even if it be filled completely, it nevertheless remains something else. And actually this is how it should be. It is the only way of perpetuating that love which we do not want to relinquish.*

*Sigmund Freud. In a letter to a colleague who had a child die.*

There can be hope in the grief that follows such brief lives. A hope that this brief life will be remembered by others, will remain close to them in their hearts; that they will find reason to find joy and renewed life in the days to come, that family will in fact be there for them and that we—as friends, caregivers, co-workers, neighbors, and church goers—will not forget their needs, their love, nor their empty space that cannot be filled.



# Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care  
Organization



---

## Bibliography

Sumner, L. (2003, August). Taking Palliative Care into Pregnancy and Perinatal Loss: A Model for Collaboration. *NAPSW Forum*.

Sumner, L., Kavanaugh, K., & Moro, T. (2006, Jan/Mar.). Extending palliative care into pregnancy and the immediate newborn period. State of the practice of perinatal care. *Journal of Perinatal and Neonatal Nursing*, 20(1), 113-116.

Field, M. J., & Bermann, R. E. (Eds.). (2003). *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*. Washington, DC: The National Academies Press.

SHARE—Pregnancy and Infant Loss Support, Inc., National office. St Joseph's Health Center, 300 First Capitol Drive, St. Charles, Missouri, 63301-2893; 800-221-7437 or 636-947-6164; [www.nationalshareoffice.com](http://www.nationalshareoffice.com).

[www.perinatalhospice.org](http://www.perinatalhospice.org)

[www.partnershipforparents.org](http://www.partnershipforparents.org)

[www.compassionatepassages.org](http://www.compassionatepassages.org)

\* \* \*



---

## Current and Emerging Issues in Perinatal Loss and Birth Planning for Parents facing Difficult Circumstances

**Ann Fitzsimons, BS, MBA**  
[AnnCompassion@aol.com](mailto:AnnCompassion@aol.com)

**Beth Seyda, BS**  
[BethCompassion@aol.com](mailto:BethCompassion@aol.com)

This is the second part of a series highlighting key insights from the 15<sup>th</sup> National Perinatal Bereavement Conference held in Chicago in 10/06 by PLIDA, the Pregnancy Loss and Infant Death Alliance. Two presentations are summarized in this brief article. The first deals with some old and new types of unspoken losses suffered by mothers perinatally, at birth, or postnatally. The second focuses on perinatal hospice and the need for birth planning, what they are, and how to help families with a birth plan when a terminal prenatal diagnosis is evident.

### **Summary One: A New Era of Unspoken Losses**

While the loss of a baby may take on many forms, it is often an unspoken loss, and therefore, an unvalidated loss, for the mother or parents. Often done in isolation because of an associated stigma or coercion, the loss of a baby before or at birth may result in an unfavorable outcome for the mother—that is, chronic, unresolved grief.

When a “normal” death occurs, the loss is often acknowledged and validated by family, friends, one’s faith community or spiritual support, and others via rituals, flowers, cards, and other types of support. However, when a family suffers an “unspoken” loss of a baby before, at, or shortly after birth, there is no validation or acknowledgement. Instead, the woman or family may experience shame and isolation, resulting in a type of “secret bereavement.” Also, because some of these baby deaths may be a loss “by choice,” the decision may be judged and not respected. Immediate family may know, but others may not. And because no one knows, the woman is expected to go back to work or school as if nothing happened.

Some examples of both current and more emerging types of unspoken losses before birth, at birth, and after birth are presented here to raise awareness as to the diversity and complexity of factors that can cause a mother to lose a child. Identifying these losses will help healthcare professionals consider how to uniquely care for these mothers who have experienced each type of loss, some of which certainly break new ground for the healthcare field to encounter.

Before birth:

- Having an abortion for genetic abnormalities
  - These are generally wanted pregnancies where something is wrong. The parents await confirmation of the abnormality and then make a decision to terminate, or not. They try to find meaning in the abnormality and often feel that no one is to blame.
- Having an abortion for reasons of choice



# Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care  
Organization



- Key reasons women have therapeutic abortions include they can't afford the child now, there are relationship problems and they don't wish to be a single mother, and the pregnancy will interfere with their education and/or employment
- Coping with unused embryos
  - In the US, there are over 400,000 frozen embryos with no federal guidelines to regulate what happens to them
  - The US does not allow them to be donated for stem cell research; the embryos are allowed to be destroyed, but not used
  - Some families don't want to think about the frozen embryos; others want the embryos frozen indefinitely
  - Most do not wish to adopt and raise the embryos
  - There is a lack of acceptable options of what to do with these embryos.
  - It has been suggested that the embryos be transferred back to the mother's body when not ovulating for them to dissolve
  - Other families may have a closure ceremony/burial for their embryos. However, there appears to be no consistency in family involvement in the disposals.
- Multifetal reduction after infertility treatment
  - Medication or in vitro created multiples
  - They are wanted children but the parents and/or healthcare team feel they must lessen the burden on the mother to ensure health and safety for Mom and the babies
  - It's an extremely difficult decision that is kept secret, but it's often not associated with extended grief because the outcome is usually positive

## At birth:

- Giving a child up for adoption
  - May be due to the woman not being married, wanting to finish her education and/or coercion by others
  - These may be open or closed adoptions, or could be gestation for payment/surrogacy
  - The losses associated with adoption permeate throughout the entire family and all touched by the adoption: The mother loses her baby and the continuity of family generation; the mother's family loses a child, grandchild, sibling, etc; the adoptive parents may be dealing with previous loss issues of infertility and/or miscarriage; and the adoptees lose their biological parents/family and also their roots and culture
- Having an infant removed due to improper parental behavior
  - The mother uses drugs or alcohol while pregnant, which may or may not be reported to child protective services
  - Only 5% of all investigated cases result in the baby actually being removed from parents into family or stranger foster care
  - This may sometimes result in court-ordered termination of the mother's rights
- Placing a child secretly in "Safe Haven"
  - Defined as leaving an infant at a designated fire station or emergency room and a new loss since 2006

## After birth:

- Delivering a child with poor chances for life, and choosing a loving and dignified death

ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics).



- Trying to save a newborn, and then with time, realizing that nothing more can be done
- In these and other cases, palliative care and hospice options do exist:
  - These may include induced early delivery, preparation of a birth plan for an in-hospital death, perinatal hospice, or home hospice

Some suggestions of what helps to ease the pain of these losses for the mother include specific nursing and medical care and birth plans, confidentiality, anticipatory guidance, viewing of the baby, breast feeding, holding and bonding with the baby, and providing a means for the family to construct the baby's story and tell it.

## References

Caitlin, Anita, DNSc, FNP, FAAN and Rogoff, Marianne, MFA. Saying No: It's Right, But it Still Hurts. Losses Due to Parental Decisions During Pregnancy or After Birth. National Perinatal Bereavement Conference, October 2006.

Note: These presenters made the following acknowledgements:

Asken and Bloom -- Post adoption  
Baran & Pannor -- Secrecy  
Susan Bryar -- Infants with anomalies  
Drapkin, Lyerly, Steinhauser, Namey, Tulsky, Cook-Deegan, Sugarman, Walmar, Faden, & Wallach -- Stored embryos  
Finer, Frohwirth, Dauphinee, Singh & Moore -- Abortion  
Gurmankin, Sisti, Caplan -- Embryo disposal  
Hammond -- Multifetal reduction  
Kovalsky and Flager -- Women with addictions  
Father John Paris -- Early induction  
Lois Pearson -- Birth plan for in the hospital  
Patricia Roles -- Adoption  
Margarete Sandelowsky -- Prenatal diagnosis

For additional information, contact Anita Caitlin, Associate Professor of Nursing, Sonoma State University.

\* \* \*

## Summary Two:

### **Birth Planning Defined and Executed When a Terminal Prenatal Diagnosis is Present**

When a lethal prenatal diagnosis is given to a family during pregnancy, they often don't know where to turn. And while some families will choose to terminate the pregnancy, an estimated 20% will decide to deliver their babies with known chromosomal or anatomic anomalies, regardless of the anticipated outcome. This results in approximately 6,000-10,000 families a year as potential candidates for perinatal hospice, a continuum of care that may not be available to all the families who need it.

### *Perinatal Hospice Defined and Operationalized*

These speakers define perinatal hospice as a "new model of care beginning at the time of diagnosis for families who know before birth that their babies will die." An excerpt from the *American Journal of Obstetrics* proposes that this perinatal model of care include three components: (1) a prenatal diagnosis, (2) perinatal grief management, and (3) hospice care to help address the needs of the family. Support and involvement from maternal-fetal medicine, obstetricians, neonatologists,

*ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics).*



# Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care  
Organization



anesthesia services, chaplains/pastors/spiritual care, social work, labor and delivery nurses, and neonatal intensive care nurses is also recommended as part of this perinatal hospice model of care.

Perinatal hospice provides support for families of babies with prenatal lethal diagnoses during pregnancy, during and after birth, and for the baby during delivery and afterwards. Specific types of interventions or supportive care that can be offered include:

- Support during pregnancy
  - Acknowledgement and validation of the parents' sorrow
  - Respecting the parents' choice to continue the pregnancy
  - Assisting with birth planning
  - Discussing ways to celebrate and welcome baby
  - Allowing the parents to see the baby on ultrasound and provide frequent pictures for parents to keep
  - Offering support and referrals for the parents' grief
  - Referring siblings to Child Life Programs, if available
  - Suggesting Web-based updates (Caring Bridge, CarePage, etc.)
  - Providing one-on-one birth preparation and tours of the delivery area
  - Discussing decisions needed after the baby's birth (e.g., medical decisions for the baby, hospice arrangements)
  - Discussing decisions needed after the baby's death (e.g., autopsy, disposition of the body, funeral or memorial service)
  
- Support during and after the birth
  - Offering families an opportunity to see and hold their child, which may include describing the baby's appearance first, if necessary, and also emphasizing the baby's features that formed normally
  - Collecting mementos (photos, locks of hair, foot and handprints, ID bracelet, etc.)
  - Encouraging/facilitating the parents (and other family members) to create experiences and memories with the baby (bathing, massaging, dressing, singing, reading)
  - Allowing the family to have as much time with baby as they wish (even if the baby has already died)
  - Allowing parents to include siblings, extended family, friends if they wish
  - Discussing postpartum recovery, including milk supply

## *Birth Planning Defined and Executed*

Reasons to encourage a family to develop a birth plan when there is a terminal prenatal diagnosis include that it: (1) provides a framework for the parents to think about the impending labor and birth with decreased anxiety as it (2) helps them understand their options while gaining insights into what experiences with the baby they may want upon delivery.

Setting the stage for a birth plan includes gathering relevant background information, acknowledging the parents' pain, and helping the parents to set boundaries as to what their wishes and desires are upon delivery and after.

- Gathering background information may consist of profiling the mother's:

*ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics).*



# Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care  
Organization



- Infertility issues
  - Previous pregnancy and birth results;
  - History on the current pregnancy in terms of when she learned about her baby's health issues and what she's been told, whether she's named the baby, and if the staff can call the baby by name
  - Presence of siblings, their ages, and what the mother's plans are for these other children. Suggestion for a Child Life consult may be offered.
- It may also include querying the family as to their wishes regarding:
    - *Labor*, in terms of support people to be present, photographs/videotaping, birth room environment, comfort measures for mom, medication, and fetal monitoring, etc.
    - *The actual birth*, and specifically, support people to be present, a mirror, cutting of the umbilical cord, identifying who the first person to hold the baby will be, photos/videos, and special clothing/blankets
    - *After birth and medical decisions for baby*, including: if the baby goes to the NICU, will the partner stay with Mom or go with the baby, resuscitation, nutrition, meds for baby's comfort, and hospice arrangements
    - *After birth and the parents' decisions about their experiences with the baby*, including: seeing/holding/bathing baby, naming baby, gathering mementoes, baptism/a blessing, photos/videos, support staff to be present/not present, and special clothing to dress baby in
    - *The baby's death*, with consideration for wanting to keep the baby alive until a certain time (e.g., family arrives, he/she is baptized, they are able to hold the baby), to hold the baby when he/she is dying, and to have the baby at home when he/she dies
    - *After the death of their precious baby*, including wishing to hold the baby as long as possible and postpartum care for mom in terms of balancing her comfort vs. her ability think clearly and be emotionally present

It is suggested that after the birth plan is written, parents should make copies and put them with the other materials they plan to bring to the hospital when the baby is delivered.

It is also recommended that healthcare professionals involved in supportive care of the family should also be consider making referrals during the pregnancy and after the baby's birth and death to other appropriate disciplines including Child Life (if other siblings), Bereavement, and Social Work, among others.

## References

Kuebelbeck, Amy, MA and Klein, Annette, RN, ICCE. Welcoming Baby: Birth Planning and Prenatal Decision-Making for Parents Continuing a Pregnancy with a Terminal Prenatal Diagnosis. National Perinatal Bereavement Conference, October, 2006.

Calhoun, BC and Hoeldtke, NJ. The Perinatal Hospice: Ploughing the Field of Natal Sorrow. *Frontiers in Fetal Health*. (2000) Vol.2, No.5.

Catlin A, Carter B. Creation of a neonatal end-of-life palliative care protocol. *Journal of Perinatology*, 2002, 22 (3), 184-95



## Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care  
Organization



---

Hoeldtke, NJ and Calhoun, BC. Perinatal Hospice. *American Journal of Obstetrics and Gynecology*. 2001. Sept;185 (3) 525-9.

*Palliative Care for Infants, Children and Adolescents: A Practical Handbook*, edited by Brian S. Carter, MD, FAAP and Marcia Levetown, MD, John Hopkins University Press: Baltimore, 2004.

Sumner, Lizabeth, RN, BSN. Taking Palliative Care into Pregnancy and Perinatal Loss. *National Perinatal Association Bulletin*, Vol.5, No.2, Fall 2004.

[www.perinatalhospice.org](http://www.perinatalhospice.org) -- Perinatal hospice resources for caregivers and parents.

\* \* \*



---

## The NICU: A Different World

### Missy Stamper

[missi.stamper@insightbb.com](mailto:missi.stamper@insightbb.com)

Our story began May 24, 1995, when my husband, Charlie, and I were expecting our first child. There had been no complications during my pregnancy. However, at 30 weeks, I woke up one morning to membranes rupturing and contractions starting at 4 minutes apart. On the way to the doctor's office, I still wasn't extremely worried; after all, I knew of others who had been in similar situations with early labor being stopped. After 14 hours of trying to stop or at least slow down my labor (several medicines and larger than normal doses), I was sent to the University of Kentucky hospital.

I was only at UK a few minutes when the actual delivery began. As it did, our baby's heart rate dropped and vacuum suction was used to deliver him quickly. Our son, Nathan, was born weighing 1035 grams (2lbs., 4 oz.). He was only there a second; we barely got a glance at him and we heard a weak cry before he was whisked away. Many months later, we learned just how difficult a fight it was to save Nathan's life. We learned it took several attempts and many minutes to resuscitate him. They were on the verge of giving up (thank God for an ambitious resident) when something finally worked.

Around 3:00 a.m. (he was born at 10:10 p.m.) the next morning, someone finally came to tell us we could go see Nathan. We were greeted by someone who told us to wash our hands (in a sterile-like manner) in a sink that surgeons use in the movies and put on special gowns. Then, we were to walk through another double door. We had no idea what to expect as we opened the doors to the NICU. It was like stepping into a foreign land, a world we did not know existed. It was a huge room filled with round beds, lights as bright as could be (especially at 3 a.m.), beeps and buzzers going off continuously, and everywhere you looked, tiny babies. This was like nothing I could have ever imagined in my wildest dreams.

As we walked over to our baby's bed, we couldn't tell what he looked like because of all the tubes, tape, wires, and probes hooked to him. Nathan was so small, his skin was almost transparent, and he was lying very still. Charlie, a firefighter, had just finished EMS training; I, on the other hand, had no medical background at all. The nurse taking care of Nathan was very nice; she explained what was going on and what some of the equipment was doing for him. But we were in shock, completely overwhelmed by all the information we were being given, and trying desperately to understand as best we possibly could about what was happening. We came back to our room, still not realizing the grim circumstances we were just beginning to confront.

Around 8:00 a.m., we were visited by the genetic counselor, who had come to talk to us about our son. The nurses had noticed some malformations and called in the geneticist to evaluate Nathan. The genetic counselor asked us a few questions about family history, and explained to us that they believed Nathan had a chromosome abnormality called trisomy 18, but further testing would be needed to verify this. He asked if we had any questions; we didn't. I now understand that we did not have any idea of what was really happening, what prematurity meant for our new baby or what this chromosome problem meant.



## Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care  
Organization



At mid-morning, Charlie and my dad had gone to visit Nathan before I was to be discharged. The geneticist was there and told them if Nathan had trisomy 18 he would more than likely die within three months. This was the first and only conversation we had during our 84-day NICU stay regarding Nathan's prognosis.

During the three-week wait for the test results, I was constantly trying to find out what the staff knew about this deadly chromosome abnormality. Did he look like a trisomy 18 baby? How would he die if he had this? Had they seen this before? I desperately needed more information. They politely answered my tough questions with very little extra information. I was told by one nurse, "he will look fine at first, then his health will become worse." I called a nursing agency for more information and heard the hesitation in her voice as she started to read the diagnosis. I told her I already knew it was fatal, but she still had a hard time talking to me. After Nathan's diagnosis came back negative for trisomy 18, I thought he would be ok, disabled maybe, but not terminally ill. These are the things that I didn't understand fully regarding Nathan's prognosis. I was more confused and hopeful now than before.

Looking back, I believe it would have helped us tremendously if we had been able to have frequent meetings with the medical team to keep us updated on Nathan's condition and what it would mean for us as a family. Many things that were so foreign to us the first day we walked in became familiar, our way of life, our new culture. Terminology that comes so second nature to the NICU staff—ASD, PDA, VSD, sepsis, ventilator, bilirubin, apnea, bradycardia, UAC, chromosome abnormalities, and fish probes—finally had meaning to us now. Slowly and surely we came to understand this new language. The more information and understanding we received about Nathan's medical condition and equipment, the more comfortable we became in taking care of him. Just holding him for a few seconds while his bed was changed means so much to parents who can't do anything else to help their child. The more we were allowed to do for him, the more we felt like "real" parents and not just spectators in his life.

We learned over the months how scary it was to be the parent of a preemie. One day Nathan would be doing well, the next day we would wonder if he would ever come home with us. We saw our life play out again and again each time a new parent would come in with a similar chromosome problem or any devastating crisis. Many times, we would leave and come back in to empty beds, knowing that at any time, it could have been us or it maybe would be us tomorrow. Several families were asked if they wanted their babies resuscitated if they were to stop breathing, but we were not, so I naively thought we were not as close to losing Nathan as were others. We also saw many families take their babies home, while some of the families, like us, wondered if they would ever get to go home with their child. Seeing the babies go home gave all of the parents much needed hope that maybe one day we would get leave as a family, too.

Nathan continued to do all the normal things preemies were supposed to do to get to go home. One of the holes in his heart healed on its own, he kept his body temperature steady, he learned to breathe on his own, recovered from hernia surgery, and he gained weight. Finally, it happened for us, after 84 days in the NICU, we were able to take Nathan home. We were thrilled, yet extremely terrified to go home. We were leaving the safety and security of the hospital, where doctors and nurses are around 24 hours a day to validate your concerns, for home, a place that leaves all the responsibility of his fragile health to us. Nathan went home with feeding tubes, oxygen, apnea monitor, many medications, a slight heart condition, and the chromosome abnormality that we didn't have a prognosis for yet.



## Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care  
Organization



We learned to take care of all Nathan's special needs and illnesses fairly well. I even learned a Mother's intuition is usually correct, though I still had trouble convincing myself of that. He was severely delayed and had many hospital stays over the years, but he lived longer than his doctors thought possible. Nathan gave and received a tremendous amount of love.

Then on January 24, 2002, our life as we knew it came to an end. Nathan was 6 years old when he died in my arms at UK. The same hospital that brought him into the world and helped him take his first breath also helped to make him comfortable for his last breath. Nathan's chromosome abnormality was identified when he was 5 years old; it was a (14%) mosaic ring trisomy of chromosome 1, which is extremely rare. Nathan was 1 of 9 in the world with this type of chromosome abnormality. We knew soon after Nathan left the NICU he would not have a long life, and we were going to savor every second we had with him. Looking back over the last 11 years, I believe we succeeded in that and we continue to believe Nathan had a life filled with love, happiness, and he had a very special quality of life. We were blessed to have been chosen to be Nathan's parents.

Since Nathan's death Charlie and I have both gone on to use our life experiences with Nathan to help others. Charlie is a paramedic and teaches other paramedics about taking care of special needs children. We both have served on several committees (for both the hospital and our local Hospice) and speak about our experiences.

I had a wonderful opportunity to work as a parent advocate in a research project helping families access information in the same NICU where Nathan was born. Life had come full circle for me. I was on the other side this time, closely watching the parents as they went through the same things we did, my heart aching for them. I knew what lay ahead, but this time I could give these parents what I wish I had. It doesn't get any better than that.

\* \* \*



---

## Obstacles to Optimal Palliative Care in the Labor and Delivery Unit

**Gay Gale, RNC, MS**  
[gggale@comcast.net](mailto:gggale@comcast.net)

**Alison Brooks, RN, MS, CNS**  
[brooka@sutterhealth.org](mailto:brooka@sutterhealth.org)

Each year thousands of parents learn that their unborn baby has a condition that will lead to death within a short time after birth. Congenital malformations and disorders related to prematurity and low birth weight continue to be the first and second leading causes of death in the perinatal period in the US (1). Many parents will choose to continue their pregnancy despite a prenatal diagnosis of an infant with a lethal anomaly. Palliative care in the delivery room is often the treatment of choice for these infants, as well as for pre-viable premature infants. Palliative care is defined as care that prevents and relieves infant suffering and relieves the existential suffering of the family (2). For purposes of this article, palliative care, comfort care, and end-of-life care (EOL) will be used synonymously.

### *Perinatal Palliative Care at ABSMC*

Alta Bates Summit Medical Center (ABSMC) is a busy urban hospital in Berkeley, California. In 2006, the Labor and Delivery (L&D) unit managed 7565 deliveries, including those referred from the hospital's high-risk perinatal service and maternal transports from other hospitals. Among the deliveries were 17 neonatal deaths (infants born at 20 weeks or greater gestation) and 60 stillbirths.

Data on the 17 infants indicates that all received "comfort care" but none received pain management. Comfort care in L&D includes the provision of warmth and holding, suctioning of oral secretions as needed, and rituals and memory making as designated by the family. Chaplaincy, social work, and a grief support counselor are available, but may not be readily available on nights and weekends. If the infant does not die within the time the mother becomes medically stable for transfer to postpartum care, the infant and mother are transferred together to the Antepartum (AP) floor. AP staff is trained to provide comfort care and grief support resources to these families. After the infant dies, parents are referred to a free local grief support group for prenatal and neonatal loss.

Having an interdisciplinary palliative care team (PCT) has improved care received by infants at EOL and their families (3). The PCT at ABSMC meets every six weeks to discuss recent perinatal and neonatal cases, the management of upcoming deliveries of infants with lethal anomalies or marginal viability, and the development of resources for these infants and their families and the staff caring for them. Last year, perinatal staff asked the team to address problems in providing palliative care in L&D. Specific concerns were poor communication between L&D and postpartum staff regarding caregiving and paperwork, inadequate preparation for parents of what to expect following the birth of a pre-viable infant, and the management of pain symptoms. L&D nurses were not comfortable assessing and managing infant pain. The two following situations with infants of marginal viability illustrate these concerns.

Case #1: Ms. R had an uneventful pregnancy until the onset of preterm labor at 22.5 weeks. Her labor progressed despite aggressive medical intervention. Ms. R and her partner agreed with the obstetrician (OB) that resuscitation of their infant was not appropriate. At birth, the parents were shocked to see the



baby had a weak cry and was moving. They asked to have the baby taken away because they could not watch him die. L&D was very busy and there was no one available to hold the baby.

Case #2: Baby T was delivered at 23 weeks gestation and weighed 500 grams. Her parents wanted no extraordinary measures taken to maintain her life. Immediately after birth she was wrapped in blankets and given to her mother to hold. At an hour of age, she had a heart rate of 50-60 and gasping respirations. The OB called the NICU charge nurse and asked her to bring morphine to ease Baby T's dyspnea. The NICU charge nurse stated she could not do this. The OB ordered oral morphine for the infant and asked the L&D nurse to administer it. The L&D nurse refused on the grounds that this was not a routine practice and suggested that the OB should be the one to administer it. Before the morphine could be administered, Baby T died.

## Common Obstacles to Optimal Palliative Care in L&D

To help us meet these challenges, the PCT contacted colleagues in other perinatal centers to gather information about how their L&D units provide palliative care. We learned that most staff face similar problems. Common obstacles to optimal care include the following:

- Because newborn death in L&D is infrequent, nurses may be unfamiliar with available grief support resources. They may be unfamiliar with options for comfort care (holding, memory making, symptom management).
- Many L&D nurses receive no training in the assessment and management of infant discomfort. Most do not feel comfortable giving pain medication to a baby.
- OBs do not feel comfortable ordering pain medication for infants.
- No neonatal pain tool measures common EOL signs and sources of discomfort such as dyspnea, agonal breathing, gasping, edema, or seizures.
- L&D nurses may have little time to provide cultural, emotional, and educational support to parents about the baby's appearance and what to expect during the dying process.
- In busy L&D units, the focus is often transferring the mother to postpartum care as soon as possible.
- Grief support and memory making activities may be passed on to staff who are not readily available, such as the chaplain or grief support counselor.
- The infant has no physician. The OB is often not involved with the care of the dying infant. In some L&D units, the OB does not attend the delivery of pre-viable preterm infants.
- In teaching hospitals with attending obstetrical and pediatric staffs, there may be shunting of responsibility for the infant's symptom management between the two departments.
- Antenatal care plans detailing the parents' wishes are not transferred to L&D prior to delivery.

### *What is Optimal Palliative Care?*

Although there is an abundance of literature advocating models of care for perinatal hospice and palliative care (4-11) there is a dearth of information about the actual implementation of this care when the family arrives at the hospital to deliver their infant.

A comprehensive family-centered model of perinatal palliative care for infants with lethal anomalies has been described by Leuthner (10). The model includes a standardized palliative care plan that is individualized by the perinatal medical team to guide care in L&D and home, if the infant survives. The



care plan includes documentation about the infant's prenatal diagnosis, comfort measures, selected medical interventions (including pain medication dosages), spiritual care, and consultations. Further care is directed, depending on whether the baby dies in the hospital or goes home.

Antenatal counseling and planning is not always possible, as in cases like those described above with marginally or pre-viable preterm infant. If there is time, the OB or L&D staff can discuss comfort care options with the family prior to the birth, using relevant portions of palliative care plan. Leuthner also describes management of the infant whose anomaly or malformation has not been diagnosed prenatally; the delivery room "surprise." He suggests that these infants should be supported medically until a diagnosis and prognosis can be determined (10).

### *Challenges with Pain Management for the Infant in L&D*

Advances in neurobiology support the idea that the fetus and newborn is able to experience acute, established, and chronic pain (12). Not all infants at EOL show signs of pain. Pain assessment may also be inconclusive (13). Walden and colleagues (14) noted in 2001 that no instrument had been developed to assess pain in neonates at EOL, and this continues to be true. Extremely premature infants like the infant in Case #2 may or may not display signs commonly measured by neonatal pain tools (facial grimacing is an example). Conversely, infants may display signs like dyspnea that are not measured by pain tools. Therefore, perinatal nurses caring for these infants need to be aware of common signs of pain and discomfort.

Not all infants at EOL need pain medication; however, all should be assessed for pain signs. If signs of discomfort are present, the nurse should feel comfortable asking for and administering medication in addition to providing non-pharmacologic comfort measures. When the nurse is not comfortable assessing or managing infant pain, consultation with neonatal staff should be available. An alternate plan for administration of pain medication to infants in L&D is used at Vanderbilt Children's Hospital in Nashville, Tennessee. When appropriate, the NNP or NICU physician is called to render this care. The need for this care is relatively infrequent (15).

### *UCSFMC's Order Set for Comfort Care in L&D*

Our colleagues at the University of California at San Francisco Medical Center (UCSFMC) have recently implemented a standard order set for perinatal comfort care, including morphine for signs of discomfort. The order set includes information about care goals, referral information for social work and spiritual care, provision of sibling support through child life services, contact information for the perinatal/neonatal palliative care resource team, and information about pain assessment, treatment, and medications (see the Appendix to this article).

UCSFMC has a high-risk perinatal service as well as a fetal surgery clinic. According to Molly Killion, RN, Perinatal Educator, there are 1-5 perinatal hospice patients who deliver there each month. Since implementation of the order set in 2005, there is less frustration about management of the infant. The focus of care has become death with dignity. Prior to the delivery, the L&D nurse prepares the family for what to expect and discusses options for holding and memory making. Prior to administration of pain medication, the nurse assesses the parent's perceptions of the infant's pain. Killion reports that the biggest challenges with palliative care in L&D are time constraints and keeping the ratio of nurse to family 1:1.



---

*A Call for the Creation of a Perinatal End-of-Life Care Protocol*

In our informal gathering of information about the state of the art of perinatal palliative care, it seems that, like ABSMC, many L&D units are independently struggling to improve care. We hear the call to provide perinatal hospice programs and to provide exemplary comfort care to infants and bereavement care to families. What we don't know enough about is how other hospitals are meeting these challenges. We have a lot to teach each other how to meet the dilemmas we face.

The publication of "Creation of a Neonatal End-of-Life Palliative Care Protocol" (2) in 2002 helped inspire many NICUs to improve their palliative care, including ABSMC. The authors used Delphi methodology to solicit information from interdisciplinary professionals at 97 locations. The article outlines consensus-based recommendations for planning and education, optimally supported death, family care, symptom management, and staff support.

We would like to take this opportunity to call for a similar process to provide recommendations for end-of-life care in the L&D unit. In the meantime, clinicians and educators familiar with programs effectively meeting the challenges of perinatal loss are encouraged to share their knowledge and experience so that we may all move toward a higher standard of care.

## REFERENCES

1. Hamilton BE, Minino AM, Martin JA, Kochanek KD, Strobino DM, Guyer B. Annual summary of vital statistics: 2005. *Pediatrics*. 2007; 119(2):345-360.
2. Catlin A, Carter B. Creation of a neonatal palliative care protocol. *J Perinatol*. 2002; 22(3):184-195.
3. Gale G, Brooks A. Implementing a palliative care program in a newborn intensive care unit. *Adv Neonatal Care*. 2006; 6(1):35-53.
4. Breeze ACG, Lees CC, Kumar, A, Missfelder-Lobos HH, Murdoch EM. Palliative care for prenatally diagnosed lethal fetal abnormality. *Arch Dis Child Fetal Neonatal Ed*. 2007; 92:F56-F58.
5. Calhoun BC, Hoeldtke NJ, Hinson RM, Judge KM. Perinatal hospice: Should all centers have this service? *Neo Netw*. 1997; 16(6):101-102.
6. Hoeldtke NJ, Calhoun BC. Perinatal hospice. *Am J Obstet Gyn*. 2001; 185(3):525-529.
7. Howard ED. Family-centered care in the context of fetal abnormality. *J Perinat Neonatal Nurs*. 2006; 20(3): 237-242.
8. McDonald H. American Academy of Pediatrics, Committee of Fetus and Newborn. Perinatal care at the threshold of viability. *Pediatrics*. 2002; 110:1024-1027.
9. Leuthner SR(a). Fetal palliative care. *Clin Perin*. 2004; 31:649-665.
10. Leuthner SR(b). Palliative care of the infant with lethal anomalies. *Pediatr Clin N Am*. 2004; 21:747-759
11. Sumner LH, Kavanaugh K, Moro T. Extending palliative care into pregnancy and the immediate newborn period: State of the practice of perinatal palliative care. *J Perinat Neonatal Nur*. 2006; 20(1): 113-116.
12. Anand KJS, et al. Summary proceedings from the neonatal pain group. *Pediatrics*. 2006; 117(3):s9-22.
13. Stringer M, Shaw VD, Savani RC. Comfort care of neonates at the end of life. *Neonatal Netw*. 2004; 23(5):41-46.
14. Walden M, Sudia-Robinson T, Carrier CT. Comfort care for infants in the neonatal intensive care unit at end of life. *Newborn Infant Nurs Rev*. 2001; 1(2):97-105.
15. Carter, Brian. Personal communication, 03/12/07.
16. Memory Boxes available at Memories Unlimited. [Info@MemoriesUnlimited.com](mailto:Info@MemoriesUnlimited.com). Accessed 03/14/07.
17. RTS Bereavement Training Programs [homepage on the Internet]. La Crosse, Wis: Gunderson Lutheran Bereavement Services. Available at: <http://www.bereavementprograms.com/news/education.html>. Accessed 03/14/07.



# Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care Organization



PROOF VERSION #1 10/26/06

## UCSF Medical Center

Orders must be written in black or blue ink. Nurse transcribing the orders will indicate the transcription by signing their name and classification, the date and time the transcribing is completed. When an order is discontinued, write "Discontinue" giving date and naming order.

UNIT NUMBER

PT NAME

BRNCHDATE

DATE	TIME
Allergies: _____ <input type="checkbox"/> None Newborn Wt _____ kg	

LOCATION

DATE

### 15 LONG NEONATAL COMFORT CARE ORDERS

1. Admit to:  Well Baby Nursery. Notify Unit Service Coordinator to use VIP field when admitting baby and choose "comfort care".
2. Diagnosis:  Extreme Prematurity  Fetal Anomalies  Other: \_\_\_\_\_
3. DO NOT RESUSCITATE
4. Estimated Fetal Weight \_\_\_\_\_ kg
5. Vital Signs: Heart rate & respiratory rate at delivery and prn change in status.
6. Initiate Non-Pharmacologic Comfort Measures: Swaddle infant in warm blankets, hold infant.
7. PROVIDER MAY CHOOSE ONLY ONE ROUTE  
 If newborn showing signs of distress or pain after non-pharmacologic measures,  
 Morphine sulfate \_\_\_\_\_ mg (0.2 mg/kg/dose) IM or SQ Q 15 minutes x 2 doses prn signs of distress  
**OR**  
 Morphine sulfate oral solution \_\_\_\_\_ mg (0.5 mg/kg/dose) buccal (side of mouth between cheek and gum) Q 15 minutes x 2 doses prn signs of distress.  
 (Additional doses may be ordered by the MD if necessary)
8. See 15 Long Procedures: Palliative Care for Non-Viable Infants in the Delivery Room  
 Death Procedure for Neonatal and Fetal Loss  
 Perinatal Comfort Care Room Use
9. Refer to Social Worker.
10. Refer to Spiritual Care Services.
11. Pull appropriate morgue pack for a live birth (manila-colored) for the MD to complete.
12. Notify MD for death pronouncement when absence of heart rate and respirations detected.
13. Other:

115-001 (Rev. 10/08) Wskw01v ORIGINAL MEDICAL RECORD COPY YELLOW NURSING COPY

Signature _____	M.D. # _____	Time _____	Date _____	Pager # _____
FLAG CHART TO INDICATE NEW ORDER	Checked by _____	R.N. Time _____	Date _____	



# Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care  
Organization



PROOF VERSION #1 10/25/06

**Neonatal Palliative Care** is a philosophy of care that includes a collaborative, interdisciplinary model for delivering care to infants with life-threatening conditions and their families. Palliative Care can occur concurrently with curative or life-prolonging therapy, or it may be the primary focus for comfort care at the end of life.

## Goals of Palliative Care include:

- To relieve physical, psychosocial and spiritual suffering.
- To achieve the best possible quality of living and dying for patients and their families.
- To enhance and maximize the family's strengths and coping.
- To prepare the family for expected/potential life changes.
- To provide care that is sensitive to personal, cultural and religious values, beliefs and practices.

## About the Perinatal and Neonatal Comfort Care Rooms

The Perinatal/Neonatal Comfort Care Rooms (M1524 and M1506) are located on 15 Moffitt. The rooms are appropriate for infants and families who require inpatient care for pain and symptom management at the end of life.

The Comfort Care Room Use policy is available online at: <http://nursinginternal.ucsfmedicalcenter.org>.

## Social Work Services

A social worker will provide social work services. The 15L front desk can identify the available social worker. Social Workers provide support to children/families and consultation to staff regarding:

- Transition to palliative care
- Psychosocial and needs assessment
- Advance care planning (DNR, and funeral/burial services)
- Coping and grief counseling
- Bereavement counseling, referrals and follow-up (debriefing and autopsy review, community resources)

## Spiritual Care Services

Children/families dealing with life-threatening conditions or end-of-life issues often find it comforting to speak to someone with a religious/spiritual background. Many individuals wish to speak with someone from their own religious/spiritual tradition. A chaplain is available 24 hours a day to:

- Offer spiritual and emotional support
- Conduct or arrange for religious/spiritual rituals
- Join with families in reading scripture or other spiritual literature

## Pain Assessment

- Include parents' perceptions in assessment
- Assess child's pain while moving him/her. Ask: Can parent hold child without evidence of pain?
- Reassess often, especially near end of duration of action of pain medication

## Pain Treatment Principles

- Encourage family to hold newborn as much as they desire
- Keep infant wrapped in warm blankets and keep room temperature warm.
- Never leave baby unattended while still alive.
- Morphine can be used effectively via oral route.
- Anticipate and prevent pain when possible; teach parents to assess pain and expect relief.
- Utilize non-pharmacologic methods for pain and anxiety relief.
- Utilize treatment methods that are simple and do not cause pain, and give the child/family the most control.



---

## Providing Emotionally Supportive Care to Parents as They Face Decisions after Prenatal Diagnosis of a Baby's Life-Limiting Condition

Deborah L. Davis, PhD

When parents receive a diagnosis that their unborn baby has a life-limiting condition and will likely die before or shortly after birth, they face a multitude of agonizing decisions. As a health care practitioner who works with these families, whether you are a counselor, physician, midwife, or nurse, you can provide critical support to parents as they make the pivotal decision: whether to terminate or to continue the pregnancy.

Because discussions about painful decisions are never easy, it can be tempting to focus on medical issues and ignore the emotional ones. And of course, you do need to convey important medical details and options to the parents. But when parents are in emotional shock or turmoil, they won't be able to absorb the information you wish to impart. First, they require emotional support.

When you first help parents navigate the emotional landscape, you are enabling them to move past their shock and manage their turmoil, which equips them to navigate the medical landscape. With emotions out on the table, when you start discussing the medical facts, options, and plans, you will probably find that parents are more able to fully participate in these difficult conversations. Attending to emotions also assists the parents in their decision-making process, as they need to do the heartfelt work of clarifying their values, evaluating the options, and determining the best interests of their precious baby.

Two key elements of emotional support are (a) providing a "safe holding environment" and (b) maintaining "therapeutic boundaries." While both elements address parents' needs (and indeed, "a" requires "b"), "safe holding" focuses on providing for the parents, and "boundaries" focuses on providing for yourself—so that you can be most effective and professional in your work with families.

### Providing a Safe Holding Environment

When parents receive the devastating news of their baby's condition and prognosis, they are thrown into crisis. Their wishes and dreams for this baby's bright future are crushed, and they confront a range of painful emotions, including disbelief, anger, guilt, failure, incompetence, isolation, disappointment, and sorrow. As they try to adjust their expectations from an imagined healthy baby to the harsh reality of a baby who will die, they must also adjust their vision of the future from "raising this child to maturity" to "relinquishing this child to an untimely death." Instead of figuring out newborn care, they must figure out end-of-life care. In order for them to make these adjustments, they benefit from having a *safe holding environment* in which they can gradually face their baby's impending death, express painful feelings and unthinkable thoughts, and figure out how to make the personal and parenting adjustments necessary.

How can you create a safe holding environment for parents? First, simply tell them that part of your job is to provide emotional support as they figure out how to proceed, how to cope, and how to adjust. Then ask them how they are doing, *really* doing.

In "holding" parents, you are only required to listen, reflect, empathize, and answer the questions they pose. To do this effectively, *sit down* with parents, and give them the time they need to process the



---

diagnosis, vent their feelings, and ask their questions. If you can be mindfully comfortable with silences, you'll give them the space they need to find their words, and they can reap solace from your calm presence. Also be comfortable with answering the tough questions simply and honestly with "I don't know," or "We cannot be certain."

Resist rushing them, interrupting them, talking at them, trying to "fix" them, or offering platitudes such as, "Try to look on the bright side," or "This too shall pass." Instead, hear them out and acknowledge their feelings by reflecting back what they are telling you. "You have every right to be angry." "This is so devastating for you." "It's so hard to believe."

You can also gently assure the parents that their feelings and thoughts are normal reactions to a heart-wrenching situation, and that they are not alone— many other parents have gone before them and experienced these same reactions. Parents find immeasurable comfort in knowing that they are neither "crazy" nor the only ones. You can also assure them that their feelings of guilt, while normal, are misplaced. "It's normal to feel responsible, even though you did nothing wrong."

Each time you meet with parents, ask, "How are you doing with all this? What does this feel like for you? What are your concerns?" Continue to help them verbalize and normalize their feelings. Offer them the attention *and* the space they need.

When parents can express themselves without fear of being judged, dismissed, or "fixed" by you, they can see you as their ally and teammate, which makes for a trusting, collaborative relationship. This therapeutic relationship is the foundation of the safe holding environment you provide parents, and in this context, the parents can hear you when you present explicit medical information. Trusting you, they can master the reality of their baby's condition, and understand that it is reasonable to **not** pursue intensive, experimental, or risky medical intervention with such a clearly fatal prognosis. They can also negotiate the uncertainties with you in their corner, knowing that you will help them make decisions when their baby's condition or palliative needs become more clear.

In this holding environment, you also can offer the medical options with clear information about palliative, end-of-life care and birth planning, and the parents can face these tough decisions—whether it is best to continue the pregnancy as long as possible under perinatal hospice care, or to end the pregnancy early by inducing labor with the option of spending time with the baby, or to end the pregnancy by abortion, usually without the opportunity to see the baby's intact body. And you can find satisfaction in knowing that you provide the holding environment that makes it possible for parents to tap into their ability to navigate the emotional *and* medical terrain, which fosters healthy adjustment during and after their baby's death. And you can find this satisfaction, *whatever decisions parents make*.

Many health care practitioners are challenged by this last bit— *whatever decisions parents make*. It is normal to have a bias, to imagine, or perhaps know, what course of action you would take if you were pregnant with a baby diagnosed with a fatal condition. In order to work with these parents, it is not necessary to rid yourself of any bias, but to *be aware of your biases*, so that you can keep those to yourself, and separate from your professional contact with parents. Which brings us to the other piece of providing emotional support to parents— *maintaining therapeutic boundaries*.

## Maintaining Therapeutic Boundaries



## Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care  
Organization



Maintaining therapeutic boundaries is both a necessary aspect of providing a safe holding environment for parents, and of immeasurable benefit to you, the practitioner. On one hand, maintaining boundaries is what allows you to provide a holding environment that is supportive rather than controlling for parents, and on the other, it's what enables you to work with families in crisis and bereavement without feeling emotionally overwhelmed or protectively detaching yourself.

For the parents, your therapeutic boundaries support them in their effort to decide for themselves what's in the best interests of their child. You care about families and their adjustment, but rather than trying to influence their decision or control their outcome, you provide the holding environment that enables them to adjust to their baby's reality at their own pace, sort through their own conflicting feelings, and clarify what *they* really think, and what sort of life, however brief, *they* want this child to have. Your maintaining therapeutic boundaries makes this individual expression possible, and is an integral part of providing appropriate support to families.

For you, maintaining therapeutic boundaries entails practicing with balance and integrity. You hold a balance between relatedness and separateness, such that you build a warm rapport with parents and you guide them toward independence, competence, and confidence, rather than dependence. Your caregiving has integrity when you are complete, separate, and whole as an individual. You are self-aware and reflective about the emotionally challenging aspects of working with families in crisis and bereavement. Conscious of your emotions, biases, strengths, and vulnerabilities, you do not function out of your own neediness. You don't overstep the parents' roles, and you don't feel the need to rescue the baby, nor the parents from the situation or themselves. And ideally, your workplace offers *you* a safe holding environment, where you and your colleagues can express yourselves, process your grief, and learn from and support each other.

For you, maintaining therapeutic boundaries also entails an attitude of open acceptance and letting go, as in, "This is their journey, it is not mine. It is not my job to tell them where they should go, but to point out the different paths available and walk with them, not for them." Walking with, not for, is a good way to stay connected to families without feeling overwhelmed by the challenges and feelings they face. This requires differentiation between oneself and the parent, and maintaining a fluid balance between empathizing with them and holding onto your own perspective: "This is happening to them, not to me. I feel empathy and understand their feelings, *and* I am aware of my own feelings and biases, and how I am affected by them and their situation. Even as parents often appear to be overwhelmed by this situation (which is only natural!), I recognize that they are strong and possess the competence to figure out what is best for themselves and how they want to proceed." Walking with, not for, you make room for parents to follow their own hearts, intuitions, and values. Whether parents choose to terminate or continue their pregnancy, you can maintain a supportive, rather than controlling/overinvolved or detached/underinvolved attitude. And instead of feeling chronically overwhelmed or alienated, you are balanced between separateness and relatedness. You can feel appropriately engaged (not enmeshed) with families, which is a cornerstone of high quality, relationship-based care.

Also remember that your therapeutic relationship with the parents doesn't empower them, but rather it helps them get in touch with the power they already possess to determine and act in the best interests of their baby. Appropriate and therapeutic support can also promote the parents' bond with their baby, such that instead of reacting in emotional pain and fear, they can respond with emotional health and love. For you, the result is knowing that you provide parents with what they really need— a safe holding environment and therapeutic boundaries— fostering their ability to be true to themselves and their baby, whether their ultimate decision is to terminate or continue the pregnancy.



Walking the emotional journey with parents will ultimately make your job easier. By providing a safe holding environment, you give parents a chance to process the news and settle down so that they can begin to absorb the medical details and options. By maintaining therapeutic boundaries you give parents the space and support to make the decisions that are best for themselves and their baby. And with healthy boundaries, integrity, and balance, you reap the benefits of feeling effective and fulfilled in this important work you do.

### **Suggested Reading**

Beattie, M. *Codependent No More: How to Stop Controlling Others and Start Caring for Yourself & Beyond Codependence*: In One Volume. New York: MJF Books, 1989;1992.

Dailey AA, Zarbock S (Eds.) *Hospice Care for Children* (2<sup>nd</sup> edition.) New York: Oxford University Press, 2001.

Barnsteiner JH, Gillis-Donovan J. Being related and separate: A standard for therapeutic relationships. *Maternal Child Nursing Journal*. 1990; 15(4):223-4;226-8.

Bruns DA, McCollum JA. Partnerships between mothers and professionals in the NICU: caregiving, information exchange and relationships. *Neonatal Netw*. 2002;21(7):15-23.

Carter, BS, Levetown M (Eds.) *Palliative Care for Infants, Children, and Adolescents*. Baltimore: Johns Hopkins University Press, 2004.

Goldman A, Hain R, Liben S. *Oxford Textbook of Palliative Care for Children*. Oxford: Oxford University Press, 2006.

Koulroutis M. (Ed.) *Relationship-Based Care: A Model for Transforming Practice*. Minneapolis: Creative Health Care Management, 2004.

Kuebelbeck, A. *Waiting With Gabriel: A Story of Cherishing a Baby's Brief Life*. Chicago: Loyola Press, 2003.

Raines C, Ewing L *The Art of Connecting: How to Overcome Differences, Build Rapport, and Communicate Effectively with Anyone*. New York: Amacom, 2006.

Stern NB. Management of Clinical Problems and Emotional Care: Early Emotional Care for Mothers and Infants. *Pediatrics*. 1998; 102(5): 1278-1281.

*Deborah L. Davis, Ph.D. is a developmental psychologist and writer who specializes in the emotional aspects of perinatal and neonatal crisis and bereavement. Her books include Empty Cradle, Broken Heart and Loving and Letting Go. She is currently working with Amy Kuebelbeck on a perinatal hospice book for parents, A Gift of Time (www.perinatalhospice.org).*



---

## Frequently Asked Questions: Perinatal Loss

**Donna Armstrong**

[darmstrong@hospicebg.com](mailto:darmstrong@hospicebg.com)

### **What terms are used to discuss early pregnancy loss? What is the difference between perinatal and neonatal?**

There are numerous terms used to discuss perinatal loss. Please read the glossary below for definitions of many of the terms heard in discussions regarding perinatal loss.

**Perinatal** is defined as the period from the latter part of pregnancy and the early postnatal period (five months before the birth and one month after the birth).

**Neonatal** is the period just after birth (28 days).

**Spontaneous abortion (SAB)** is the expulsion of all or any part of the placenta or membranes, with or without identifiable fetus prior to the 20<sup>th</sup> week of gestation.

**Miscarriage** refers to a pregnancy that ends on its own before it is viable. It is also the lay term for spontaneous abortion.

#### **Types of Miscarriage:**

**Incomplete Miscarriage** occurs when not all products of conception stay in the uterus.

**Complete Miscarriage** occurs when the embryo or products of conception have been expelled from the uterus.

**Missed miscarriage** occurs when the embryo dies but is not expelled from the uterus. In this case, women can experience a miscarriage without knowing it.

**Blighted ovum** refers to a fertilized egg that didn't develop or an egg whose development ended very early.

**Etopic Pregnancy** occurs when the fertilized egg implants itself in a place other than the uterus, usually the fallopian tube.

**Molar pregnancy** occurs when there is a problem during the fertilization process that leads to the growth of abnormal tissue within the uterus.

**Early Pregnancy Loss** refers to miscarriage, ectopic pregnancy, and medical interruption of pregnancy. This may also be referred to as a **perinatal loss**.

**Medical Interruption of Pregnancy** refers to termination of pregnancy by either procedure or medication due to mother's health risks or diagnosis of fetal anomalies.



---

**Embryo** is the term used to refer to the fertilized egg from the time of conception until the beginning of the 3<sup>rd</sup> month of pregnancy. After that time it is referred to as a fetus or unborn baby.

**Fetus** is the term used for the unborn child from the beginning of the third month after conception until birth.

**Products of Conception** refers to fetal tissue and placenta.

**Gestation** is the time from conception until birth.

**Stillbirth** is classified as fetal death after 20 weeks gestation with fetal weight being 350 grams or more.

**Newborn death** occurs when the newborn dies within 28 days. This is also referred to a neonatal death.

**Recurrent pregnancy loss** is the miscarriage of 2 or 3 consecutive pregnancies in the 1<sup>st</sup> trimester or early in the 2<sup>nd</sup> trimester. This is also referred to a **recurrent miscarriage**.

## References

American Pregnancy Association, <http://www.americanpregnancy.org/pregnancycomplications/miscarriage.html>

March of Dimes, [www.marchofdimes.com](http://www.marchofdimes.com)

Midland, D., Gensch, B. & Rybarik, F. (eds.). RTS Bereavement Training in Pregnancy Loss & Newborn Death. La Crosse, WI: Bereavement Services, 2004

Obgyn.net, <http://www.obgyn.net/>

Oxford English Dictionary, <http://dictionary.oed.com>

\* \* \*



---

## Educational Resources

**Karen Paradise Baranowski, RN**

[Karen.baranowski@intermountainmail.org](mailto:Karen.baranowski@intermountainmail.org)

This section identifies a broad array of educational resources relevant to perinatal loss in pediatric palliative care. These include links to web resources and an unannotated bibliography of resources.

If you have any items you would like added to this section in future issues, please send information to the above email address.

### Web Resources—Perinatal Loss

**[Angel Babies Forever Loved](http://www.angels4ever.com/)**

<http://www.angels4ever.com/>

Support for those suffering loss due to miscarriage, stillbirth, neonatal loss, or SIDS.

**[HAND - Helping After Neonatal Death](http://www.handonline.org/index.html)**

<http://www.handonline.org/index.html>

Information and support for parents, families, and health care providers dealing with loss of a baby before, during, or shortly after birth.

**[Hygeia](http://www.hygeia.org/home.htm)**

<http://www.hygeia.org/home.htm>

Information and support for perinatal health, loss, and bereavement.

**[MEND - Mommies Enduring Neonatal Death](http://www.mend.org/home_index.asp)**

[http://www.mend.org/home\\_index.asp](http://www.mend.org/home_index.asp)

Christian support group for those experiencing miscarriage, stillbirth, or early infant death.

**[SHARE Pregnancy and Infant Loss Support](http://www.nationalshareoffice.com/)**

<http://www.nationalshareoffice.com/>

(800) 821-6819

Organization with over 130 local chapters worldwide that offers support to parents and others who have experienced the death of a baby through early pregnancy loss, stillbirth, or newborn death.



## Selected Resources on Perinatal Loss

The following resources are specifically focused on perinatal loss. It is recommended that you examine a specific title for yourself to determine its strengths, weaknesses, and suitability for those to whom you might offer it.

### For Caregivers and Professionals

- [\*A Caregivers Handbook to Perinatal Loss.\*](#) Gary Vogel, A Place to Remember, 1996. ISBN: 0965084809
- [\*A Most Important Picture.\*](#) Centering Corp, 1985. ISBN: 1561230146
- [\*Loss during Pregnancy or in the Newborn Period: Principles of Care with Clinical Cases and Analyses.\*](#) James R. Woods and Jennifer Woods, 1997. ISBN: 0965531007
- [\*Pastoral Care in Pregnancy Loss.\*](#) Rev. Dr. Thomas Moe, Haworth Press. ISBN: 0789001969

### Prenatal Decision Making

- [\*A Time to Decide, a Time to Heal : For Parents Making Difficult Decisions about Babies They Love.\*](#) Molly A. Minnick, et al, Pineapple Pr, 4th edition 1992. ISBN: 1878526391
- [\*Precious Lives, Painful Choices : A Prenatal Decision-Making Guide.\*](#) Sherokee Ilse, Wintergreen Press, 1993. ISBN: 0960945695

### Stillbirth/Infant Death

- [\*A Piece of My Heart: Living Through the Grief of Miscarriage, Stillbirth, or Infant Death.\*](#) Molly Fumia, Conari Press, 2000. ISBN: [1573245100](#)
- [\*An Empty Cradle, a Full Heart: Reflections for Mothers and Fathers after Miscarriage, Stillbirth, or Infant Death.\*](#) Christine O'Keeffe Lafser, Loyola Press. ISBN: 0829411739
- [\*Dear Cheyenne: A Journey into Grief, a Collection of Angels & Love, a Celebration of Motherhood.\*](#) Joanne Cacciatore, Mothers in Sympathy & Support, 1999. ISBN: 0966301501
- [\*Empty Arms: Coping After Miscarriage, Stillbirth and Infant Death.\*](#) Sherokee Ilse, Wintergreen Press, Revised Edition 2000. ISBN: 0960945660
- [\*Empty Cradle, Broken Heart: Surviving the Death of Your Baby.\*](#) Deborah L. Davis, Fulcrum Pub, 1999. ISBN: 1555913024
- [\*Ended Beginnings: Healing Childbearing Losses.\*](#) Claudia Panuthos and Catherine Romeo, Bergin & Garvey, 1984. ISBN: 089789054X
- [\*Free to Grieve - Always Precious in Our Memory: Reflections After Miscarriage, Stillbirth or Neonatal Death.\*](#) Maureen Rank, Bethany House, 1985, ISBN: 0871238063
- [\*Grieving The Child I Never Knew.\*](#) Kathe Wunnenberg, Zondervan, 2001. ISBN: 0310227771
- [\*How to Go on Living after the Death of a Baby.\*](#) Larry G. Peppers & Ronald J. Knapp, Peachtree Pub, 1985. ISBN: 093194869X
- [\*Life Touches Life: A Mother's Story of Stillbirth and Healing.\*](#) Lorraine Ash, NewSage Press, 2004. ISBN: [0939165503](#)
- [\*Love, Labour and Loss: Stillbirth and Neonatal Death.\*](#) Jo Benson, Scarlet Press, 1996. ISBN: 1857270630
- [\*Still to Be Born.\*](#) Pat Schwiebert and Paul Kirk, Perinatal Loss, 1986. ISBN 096151972X
- [\*Strong and Tender: A Guide For The Father Whose Baby Has Died.\*](#) Pat Schwiebert, Perinatal Loss. ISBN: 0961519770
- [\*Tears of Sorrow, Seeds of Hope : A Jewish Spiritual Companion for Infertility and Pregnancy Loss.\*](#) Nina Beth Cardin, Jewish Lights Pub, 1999. ISBN: 1580230172



## Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care  
Organization



- 
- *When a Baby Dies : The Experience of Late Miscarriage, Stillbirth, and Neonatal Death.* Nancy Kohner & Alix Henley, Routledge, 2001. ISBN: 0415252768
  - *When a Baby Dies: A Handbook for Healing and Helping.* Rana K. Limbo, et al, Lutheran Hospital-La Crosse, 1998. ISBN: 0960709843

### **Pregnancy after a Loss**

- *Beginning Again : SIDS Families Share Their Hopes, Dreams, Fears, & Joy.* Deborah R. Gemmill, Beachcomber Pr, 1995. ISBN: 0963034111
- *Pregnancy after a Loss: A Guide to Pregnancy after a Miscarriage, Stillbirth or Infant Death.* Carol Cirulli Lanhan, Berkeley Pub Group, 1999. ISBN: 0425170470
- *Trying Again: A Guide to Pregnancy after Miscarriage, Stillbirth and Infant Loss.* Ann Douglas, Taylor Pub, 2000. ISBN: 0878331824

### **Children and Grief**

- *No New Baby.* Marilyn Gryte, Centering Corp, 1999. ISBN: 1561230413
- *We Were Gonna Have a Baby, but We Had an Angel Instead.* Pat Schwiebert, Grief Watch, 2003. ISBN: [0972424113](#)

\* \* \*